

Reducing Epilepsy Risks



Easy read information for people with epilepsy



This leaflet shares important information to help you to live more safely with your seizures. You might call these fits.



You may need someone to support you to go through this information, to help you to understand it. This person could be someone from your family, a carer, support worker or a friend.



There are different types of epilepsy/fits. Most people get better after a fit and do not need emergency help.



But sometimes some people can be really ill with epilepsy and some people can die.



If someone who has epilepsy dies, when there is no other reason, this is called SUDEP (Sudden Unexpected Death in Epilepsy).



People might also die from epilepsy if they:

- have fits that last a long time
- have an accident during a fit
- drown when having a fit near water



There are often lots of things you and those around you (family, friends, carers, support worker and health professionals) can do to lower any risks you may have.



It is good to know about the dangers of epilepsy so that you can be safe. You can live a good and long life with epilepsy.



We hope this information will help you to make the right choices for yourself.

Things you can do:



Write down when you have a fit, what the fit was like, and how it makes you feel. It helps to keep track of when you have had a fit. Or ask someone to support you to write this down.



Share this information with your health professionals who will help you get on the right medication.



It is important for the people who support you to know what type of fits you have as some fits are more dangerous than others. For example fits that make your body shake or put you to sleep. These fits are called tonic clonic seizures.



It's important for you to take your epilepsy medication at the right time every day. You may need to take your medication with you when you go out. For example if you have emergency medication for your fits, or need to take your medication at different times in the day.



Not taking your epilepsy medication can be unsafe and dangerous. It could mean you have more fits which may get worse (they might last longer or feel stronger).



Sometimes, medications can make you feel unwell. This means you may get some side-effects.



It might be your body getting used to the medication, but if you continue to feel unwell, let your family, carers or health professionals know.



If you have any side effects, are worried or have any questions about your epilepsy medication, speak to your family, carers, support worker or your health professional.



When you go out, make sure someone who is with you knows you have epilepsy - Tell them what they should do or who they should contact if you have a fit; this could be your family, support worker or health professional.



This can help them to know what to do in an emergency; for example if you injure yourself or if your fit lasts for a long time.



Understand and follow your epilepsy care plan - Some people with epilepsy will have a care plan.



It tells people important information about how best to keep you safe; this includes information about your medications, care and support and what to do when you have a fit in an emergency.



You need to make sure this care plan is kept up to date. It can help you to make the right choices for you and your epilepsy.



Eat well - it is important to eat a healthy and balanced diet. Drinking a lot of alcoholic drinks, taking illegal drugs or both could make you more likely to have a fit https://www.nhs.uk/live-well/eat-well/



Sleep well - Sleep is very important – try to get 7-9 hours sleep each night if you can. Not getting much sleep could make you have more fits.



Tell the family member, carer, support worker or health professional who looks after your epilepsy if you are not sleeping well or if you feel tired in the morning.



Driving - If you are a driver, it's important to read the law about driving if you have epilepsy.



Having a fit whilst driving could be very dangerous and put your life and others at risk. You can find more information about this by clicking on the link: www.gov.uk/epilepsy-and-driving



How your health professional can help you to live more safely with epilepsy -Speak to a health professional, carer, support worker, or family member if your fits get worse, happen more or less often or if they make you feel different.



Changes in your fits could mean you need more help to control them and to lower your risk and help you live happy and well.



It's important to talk about how you feel - Sometimes you may feel sad, worried, or feel like you don't want to do anything.



Your feelings about your epilepsy are just as important as controlling your fits. Tell your health professional, carer, support worker or family about this.



Talk about night time fits with your health professional - You may have signs of having night time fits if you feel different in the morning.



You may wake up with injuries and not know how you got them. This could be bites on your tongue or bruising. If this is happening to you, you might need extra support or care to help you.



Pregnancy - If you are thinking about starting a family then speak to a health professional before you are pregnant (or as soon as you find out you are if it was unplanned).



Speak to your health professional about how to avoid accidents or injuries during fits - Many people with epilepsy can have accidents or get hurt when they have a fit.



It is important to think about what you or the people supporting you can do to make your home and the places you visit safer if you have a fit; for example, how to avoid falls, getting burnt or how to stay safe around water.



You can read more at: https://www.nhs.uk/conditions epilepsy/living-with/



Speak to your health professional if you are taking medication for another health condition or illness - Some medications can change how others work, so it is important that your health professional is aware if you are taking any medications as well as your epilepsy medication.



Researchers and health professionals are always learning more about risks for people with epilepsy, and what can be done to lower these risks to help people live more safely with epilepsy.



SUDEP Action can help you too -

SUDEP Action is an epilepsy charity, who have made a free app to help people with epilepsy to learn about their epilepsy risks:

www.sudep.org/epsmon



This app helps you understand what risks you might have, so you can get help to lower them. It can be taken along to your epilepsy appointments to help you talk about this.



If you would like to speak with someone about this leaflet, please contact:



SUDEP Action:

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